

# If Palliative Care Is the Answer, What Is the Question?

By J. Russell Hoverman, MD, PhD

There are patient images that stay with us. An early one is of an elderly gentleman, a sharecropper from eastern North Carolina. Weak and emaciated from his pancreatic cancer, he is wheeled into the exam room by his son. His son, having left his job as a health care worker in Washington, DC, to care for his father, lifts him into his arms and places him gently on the examination table. The patient is comfortable, and we have little to offer, so his son lifts him again, placing him back in the wheelchair to take him home and care for him until he dies.

Another, now in a rural community, is that of an elderly gentleman with lung cancer. After unsuccessful chemotherapy, he is offered a referral to an academic center. He declines, stating that he has worked on a farm all his life, understands life and death, and simply wants to be cared for at home. A third is that of a religious community that provides all that is needed for their dying members, including a free-standing nursing facility. It was there that I visited another patient dying from metastatic cancer, cared for by who were, essentially, her sisters. These patients expected to die in a certain way—a ritual of dying. Family members and the community are critical parts of this ritual and were more than willing to participate.

All of these patients had exceptional palliative care (lower-case pc: the spectrum of care for maintaining comfort for those with terminal disease) without the need for Palliative Care (upper-case PC: indicating formal consultation with a specialty trained professional). The article by Rocque et al<sup>1</sup> in this issue recommends PC as an intervention for patients with advanced cancer who experience an “unscheduled” admission to the hospital. The authors reference current literature and the ASCO Provisional Clinical Opinion (PCO)<sup>2</sup> to support this recommendation. Understanding the PCO is critical for understanding how PC fits into the broader spectrum of palliative care.

The PCO relies heavily on the article by Temel et al<sup>3</sup> demonstrating the benefit of early PC for patients with metastatic lung cancer (NSCLC) treated in an academic cancer center. On the basis of this study, the PCO recommends that “combined standard oncology care and palliative care should be considered early in the course of illness for any patient with metastatic cancer and/or high symptom burden.”<sup>3(p880)</sup>

The Temel study<sup>3</sup> involved a number of components: patients, site of service (SoS), disease, and intervention. The study can be looked at symbolically as follows:

Control arm:  $x(P) + \text{NSCLC} + \text{SoS } 1 + \text{SC } 1$   
 $\rightarrow \text{Outcome } 1$

Intervention:  $y(P) + \text{NSCLC} + \text{SoS } 1 + \text{SC } 1 + \text{PC } 1$   
 $\rightarrow \text{Outcome } 2$

where  $x(P)$  = number of patients in the control group;  $y(P)$  = number in the intervention group; SoS 1 = study site of service; and SC 1 = standard of care at SoS 1.

The PCO extrapolates these research findings into:

All  $(P) + \text{NSCLC} + \text{SoS } (1,2,\dots,x) + \text{SC } (1,2,\dots,x)$   
 $+ \text{PC } (1,2,\dots,x) \rightarrow \text{Outcome } 2$

Logically, one cannot make this jump if there are differences in the characteristics of the SoS, the SC, and even PC. The PCO authors note that PC consists of a number of components: realistic goal setting, skilled communication, and systematic symptom assessment. The place of these components individually was not addressed in the PCO. Why cannot all or some of these be part of the standard of care without the need for PC, and what can they contribute? The literature is replete with studies of these components, and as this is not a systematic review, a few are noted: (1) In a study by Wright et al<sup>4</sup> that linked remembered conversations about prognosis to better outcomes, the only SoS with more patients than not who remembered those conversations was New Hampshire Oncology-Hematology. (2) Kalisiak et al<sup>5</sup> combined physician education, systematic feedback in a peer review structure, and available PC to reduce late chemotherapy use from 21% to 7%. (3) For Dudgeon et al,<sup>6</sup> systematic symptom assessment increased detection of symptoms and improved care. (4) Lundquist et al<sup>7</sup> found that simply informing patients that their disease was terminal improved end-of-life care. (5) Blayney et al<sup>8</sup> showed, in an academic setting, that feedback to fellows reduced late chemotherapy from 50% to 20%. (6) Living wills make a difference,<sup>9</sup> and in a community where more than 85% of hospitalized patients have advanced directives, 98% will chose to forego aggressive care.<sup>10</sup> (7) Alternative payments structures may make a difference.<sup>11,12</sup> (Ironically, PC as a hospital-based discipline owes its growth to a payment system that bundled services).

Furthermore, a key characteristic of the SC arm was its aggressiveness. The administration of chemotherapy in the last 2 weeks of life is a measure of aggressiveness that crosses treatment settings. In the Temel study,<sup>3</sup> the percentage of patients who received late chemotherapy was 24% in SC and 17% with a PC intervention. Our internal Quality Oncology Practice Initiative (QOPI) practice data for spring 2012 indicate a rate of 11.6%, with a range of 6.9% to 17.5%.<sup>13</sup> This is consistent with QOPI overall averages.<sup>14</sup> Colla et al<sup>11</sup> documented a rate in the Medicare population of 14%. Recent data of Medicare patients indicate a rate less than 10% in all sites, but with considerable variability.<sup>15</sup>

The conclusion can only be that the Temel study was done at an SoS characterized by aggressive care. This may be due to the

self-selection of patients who go to academic centers: younger, predominantly white, economically better off,<sup>16</sup> and likely more optimistic regarding the benefits of current therapies.<sup>17</sup> As well, patients at referral centers may be displaced from their communities and traditional sources of support. Whatever the reason, the data are consistent in showing less aggressive care in the self-selected, predominantly community-based practices that report to QOPI. These practices likely do not have in-house PC and certainly have not had concurrent PC for their patients with metastatic disease. Although a ready intervention for some sites, PC is neither sufficient nor always necessary to achieve satisfactory end-of-life care.

What then about the Rocque et al<sup>1</sup> study? A PC intervention will likely be beneficial, but there are no clinical trial data on measuring the magnitude of benefit of PC for patients with a median survival of 3.4 months. Even so, the opportunity to prevent that unscheduled admission will have been lost. To achieve exceptional pc, a wider approach is called for. We can frame the critical components of a standard of care for patients with incurable cancer. These would include the above-mentioned (1) goal setting, (2) skilled communication, (3) systematic symptom assessment, as well as (4) easy access to PC<sup>18</sup>; (5) systematic collection of relevant metric data with a forum for continuous feedback; (6) directives and advance care plan documented in a source accessible from any site of service; (7) community resources, particularly hospice care, to provide support outside the hospital and clinic (for displaced patients, these resources may need to be identified, and in some cases, created);

and (8) alternative payment schedules that encourage teamwork and eliminates piece-work billing. PC, then, is but one piece of the puzzle that when put together can yield superb palliative care.

As I write this, another image recurs. It is of a 40ish gentleman lying unconscious in bed, feeding tube in place, in the current state for more than 10 years. Our job as his health care team over the next month was to be sure he did not die “on our watch.” He was trapped in a technologic purgatory (pre-Quinlan, pre-Cruzan) between fully living and the ritual of dying. We may be agents of this same culture of offering technologic solutions to humanistic problems. We as oncologists are privileged to be participants in the difficult transition of our patients from actively living to the ritual of dying. “On our watch” we, as a team, can offer realistic expectations, foster hope, identify willing family members, friends, and community resources, acting as a valued guide and no longer as a scientific expert.

#### Author's Disclosures of Potential Conflicts of Interest

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## References

- Rocque GB, Barnett AE, Illig LC, et al: Inpatient hospitalization of oncology patients: Are we missing an opportunity for end-of-life care? *J Oncol Pract* doi: 10.1200/JOP.2012.000698
- Smith TJ, Temin S, Alesi ER, et al: American Society of Clinical Oncology provisional clinical opinion: The integration of palliative care into standard oncology care. *J Clin Oncol* 30:880-887, 2012
- Temel JS, Greer JA, Muzikansky A, et al: Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 363:733-742, 2010
- Wright AA, Zhang B, Ray A, et al: Associations between end-of-life discussions, patient mental health, medical care near death and caregiver bereavement adjustment. *JAMA* 300:1665-1673, 2008
- Kalisiak A, Hedlund S, Gandara E: Positive impact: Integrating palliative care education and support in a community oncology practice. *J Pain Symptom Manage* 41:289, 2011
- Dudgeon DJ, Knott C, Chapman C, et al: Development, implementation, and process evaluation of a regional palliative care quality improvement project. *J Pain Symptom Manage* 38:483-95, 2009
- Lundquist G, Rasmussen BH, Axelsson B: Information of imminent death or not: Does it make a difference. *J Clin Oncol* 29:3927-3931, 2011
- Blayney DW, McNiff K, Hanauer D, et al: Implementation of the Quality Oncology Practice Initiative at a university comprehensive cancer center. *J Clin Oncol* 27:3802-3807, 2009
- Degenholtz HB, Rhee Y, Arnold RM: Brief communication: The relationship between having a living will and dying in place. *Ann Intern Med* 141:113-117, 2004
- Hammes BJ, Rooney BL: Death and end-of-life planning in one midwestern community. *Arch Int Med* 158:383-390, 1998
- Colla CH, Morden NE, Skinner JS, et al: Impact of payment reform on chemotherapy at the end of life. *J Oncol Pract* 8:e6s-e13s, 2012
- Hillman AL, Pauly MV, Kerstein JJ: How do financial incentives affect physicians' clinical decisions and the financial performance of health maintenance organizations? *N Engl J Med* 321:86-92, 1989
- Texas Oncology, P.A.: QOPI Spring 2012. Unpublished data
- Jacobson JO, Neuss MN, McNiff KK, et al: Improvement in oncology practice performance through voluntary participation in the Quality Oncology Practice Initiative. *J Clin Oncol* 26:1893-1898, 2008
- Morden NE, Chang C, Jacobson JO, et al: The CARE SPAN: End-of-life care for Medicare beneficiaries with cancer is highly intensive overall and varies widely. *Health Aff* 31:786-796, 2012
- Ford JG, Howerton MW, Lai GY, et al: Barriers to recruiting underrepresented populations to cancer clinical trials: A systematic review. *Cancer* 112:228-242, 2008
- Murthy VH, Krumholz HM, Gross CP: Participation in cancer clinical trials: Race-, sex-, and age-based disparities. *JAMA* 291:2720-2726, 2004
- Muir JC, Daly F, Davis MS, et al: Integrating palliative care into the outpatient, private practice oncology setting. *J Pain Symptom Manage* 40:126-135, 2010

